

ORIGINAL RESEARCH

Discrimination of elderly patients in the health care system of Lithuania

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Abstract

Aim: This study aimed to explore and describe the barriers that elderly Lithuanians experience with respect to going to court or other institutions to defend their right not to be discriminated regarding medical care.

Methods: We used a mixed methods approach due to the scarcity of information in Lithuania. First, the review of laws was done using the e-tar database and court cases were searched using the e-teismai database followed by policy analysis. Additional sources of information were identified searching Google Scholar and PubMed, as well as Google for grey literature. The keywords used were: ageism in patient care, discrimination against elderly, elderly and health (English and Lithuanian: 2000-2015). Secondly, we conducted in-depth individual interviews with 27 clients of newly-established integrated home care services: 13 elderly patients, and 14 informal caregivers.

Results: This study identified five groups of barriers explaining why Lithuanian elderly are hesitant to fight discrimination in the health system. The results of the study disclose the following barriers that the elderly in Lithuania face: i) the lack of recognition of the phenomenon of discrimination against the elderly in patient care; ii) the lack of information for complaining and the fear of consequences of complaining; iii) the deficiencies and uncertainties of laws and regulations devoted to discrimination; iv) the high level of burden of proof in court cases and lack of good practices; v) the lack of a patient (human) rights-based approach in all policies and in education as well as the lack of intersectoral work.

Conclusions: This study disclosed the need to: encourage training of legists and lawyers in expanding knowledge and skills in human rights in patient care; encourage training of health care professionals – the burden of leadership for this has to be assumed by universities and public health professionals; incorporate a new article in the ‘Law on the rights of patients and compensation for the damage to their health’, clearly stating where to complain in case of discrimination; create a webpage and brochures with readable and understandable information for elderly persons and their families and caregivers; establish legal consultation and mediation cabinets in health care facilities; establish an older persons’ rights protection service under the Ministry of Social Security and Labour in close cooperation with the Ministry of Health; promote sustainable results by incorporating a human rights-based approach regarding elderly persons in all policies.

Keywords: aging, discrimination against elderly patients, human rights, legislation, Lithuania, patient care.

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Introduction

Although ageism, i.e. stereotyping and discriminating against individuals or groups on the basis of their age, has been described already since 1969 by Robert Neil Butler (1), it is still prevalent, and in some societies even growing (2). Roots of ageism are gerontophobia and the fear of death, which are deeply embedded in people's minds. Discrimination against the elderly exists in all spheres of life and in patient care as well (3,4). Discrimination against the elderly in patient care combines two main actions: discriminating behaviour on the ground of a patient's age and the lack of 'good behaviour' by someone who has a duty and responsibility for patients in the health context. This type of discriminating behaviour may occur when professional health care providers are not educated enough to question their own personal culture, views or attitudes (subjective causes), or when the state violates the legally-recognized human rights principles by creating discriminatory policies. In one of the interviews, an over-80-year-old man said *"It surprised me how children and young people show love and respect for the elderly in their family and yet disrespect and ignore the elderly outside"* (5). This 'outside' can be a hospital, hospice or elderly home or system of laws. French researchers Herr et al. (6) disclosed that *'socioeconomic position influenced the risk of having unmet health care needs, but the main risk factors identified were advanced age and homebound status.<...> The oldest-olds are the most affected by unmet health care needs'. The United Nations Special Rapporteur believes '...that the promotion and protection of human rights of older persons is not only in the interest of senior persons, but should also be of concern to everyone, because every person ages'* (7).

Europe is aging and Lithuania is aging twice as fast as Europe on the whole (8). The main causes are low birth and high emigration rates of younger Lithuanians. At the beginning of 2015, the population of Lithuania was 2.9 million, including more than 650,000 (or 22.3%) of pension-age individuals (work according to a moving age-scale in 2015 ends at 61,4 years of age for women and 63,2 for men) (9). The elderly have become a significant part of society, but this does not mean in any way that they have become a privileged part of society.

Europe, including Lithuania, has clear legal protection - a convention - for children (10), but does not have a convention for older persons. Both are vulnerable groups and need more protection than the working age subgroup of the population. Elderly are only covered indirectly, e.g. by the European Charter of Patients' Rights (11), or the Council of Europe in its Convention for the Protection of Human Rights and Dignity of the Human Being (12). Policy makers do not seem to be very interested in an additional document specifying the elderly person's rights (13), but it is time to connect patient care and public health law with a human rights-based approach. According to Gostin (14): *"...public health law is the study of the legal powers and duties of the state, to assure the conditions for people to be healthy. The prime objective of public health law is to pursue the highest possible level of physical and mental health in the population, consistent with the values of social justice"*.

According to the Eurobarometer survey, "Discrimination EU 2012", discrimination against old age and disability is very frequent in Lithuania, respectively 59% and 45% percent (15). Lithuanian research reveals a deep and ingrained discrimination in all fields of life, especially in the labour market (16). Although discrimination of elderly occurs also in patient care in Lithuania (17,18) there is lack of multi-faceted and comprehensive research showing how widespread the discrimination of elderly in fact is. Discrimination in patient care in Lithuania resembles the allegory about the three wise monkeys that hear, see, and speak no evil. But in real life an older person faces many discriminating phrases like: 'What do you expect at your age?'; 'You don't need breast at your age'; 'Come on, pensioners can wait'...and 'Never tell the ambulance operator your real age, they will not hurry'. Given this situation, questions

remain as to why Lithuanian elderly do not use institutions or courts to insist on their rights. After all, health issues are the most pertinent to survival. *“Ageist attitudes are not only hurtful; they are harmful<...> the fact is that older people get sick from disease, not old age”* (19). *“The right to health requires that facilities, goods, and services be available, accessible, acceptable, and of quality”* (20). This is not only the question of a patient’s right to health, but of the person’s human rights per se.

The research question has derived from the description of the situation in Lithuania and the aim of the research was to identify the barriers preventing elderly patients from filing legal action against experienced discrimination which could be successful and, even more, would indicate the magnitude of the problem.

Methods

In this study two main methods were employed. Firstly, a review of the legislation using the e-tar database (21). Court cases were searched employing the e-teismai database (22) followed by policy analysis. Furthermore, Google Scholar and PubMed and, for grey literature, Google were screened. The following key words and terms were used: ‘ageism in patient care’, ‘discrimination against elderly’, ‘elderly and health’ (all in English and Lithuanian: 2000-2015).

Secondly, in-depth individual interviews with elderly patients and their family members (informal care givers) were conducted to answer questions like: What is your current health care situation? What difficulties do you face concerning health care? What actions do you think you could take in order to change the situation and to receive proper medical care? The answers were analysed with the research focus on how discriminating behaviour towards elderly patients manifests in patients’ everyday day life, and what do patients and their caregivers think of taking legal action to protect their rights of access to and receipt of proper medical care. The targeted sample of informants was the users of the newly-implemented integrated home care services from ten Lithuanian municipalities (out of 21 municipalities where the services were started). The users were chosen according to their availability for an interview on the day that the interviewer was visiting the municipality. Overall, 34 patients and their care-givers were visited, but seven patients were not interviewed because they were younger than 65 years. The final sample comprised 13 patients and 14 family members. The patients were present during the interview, but seven of them were not contributing significantly because of having difficulties to express their thoughts. All informants (including the family members) were older than 65 years. The elderly patients had chronic conditions and required long-term care around-the-clock. The informal caregivers were nine daughters or daughters-in-law, and five spouses (four wives and one husband). Although the intention of interviewing family members was to hear about the person they take care of, the result always was that the carers additionally volunteered to provide information about their own experience in health care as patients. The interviews focused on informants’ experiences, perceptions, and opinions concerning medical care services.

All interviews were conducted by a team of authors (LD, RJ, RB). The interviews took place in patients’ homes and lasted 60-90 minutes each. All interviews were tape-recorded (audio) with the informants’ consent, both the patient and the family member. All three interviewers/authors repeatedly read the material, selected, and coded the ‘meaning units’ related to the manifestation of discriminating behaviour by health care providers and the opinions of taking legal action to protect the elderly persons’ rights to proper medical care. The main categories were developed and reached by the team of authors after thorough discussion.

Definitions: Discrimination: i) the unjust or prejudicial treatment of different categories of people, especially on the grounds of race, age, or sex (23), or ii) any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights (WHO) (24).

The study was conducted in accordance with the Declaration of Helsinki (25).

Results

Examination of the Lithuanian legal framework and the court practice and litigation procedure

- i) Article 29 of the Lithuanian Constitution does not mention age specifically but is inclusive in regard to equality of all persons under the law and non-restriction of rights of human beings - and contains a limited list of categories of persons whose rights cannot be restricted or to whom special privileges cannot be granted on specific grounds: *“All persons shall be equal before the law, the court, and other State institutions and officials. The rights of the human being may not be restricted, nor may he be granted any privileges on the ground of gender, race, nationality, language, origin, social status, belief, convictions, or views”* (26).
- ii) The main law, “Law on the rights of patients and compensation for the damage to their health” (27), which describes different patient rights and establishes a particular institution to which to complain (Article 23), does not mention any institution which has the authority to solve disputes regarding discrimination in Lithuania.
- iii) The law, ‘Law on Equal Treatment’ (28), which sets up the categories of discrimination and empowers the Ombudsperson to investigate alleged instances of discrimination, does not define describe discrimination in health care – whereas discrimination in the education system or labour market is clearly mentioned.
- iv) Regarding court practice and litigation procedure as of now (early 2016) there are no cases in the Lithuanian Supreme Court and other courts’ records. In 2015, Lithuania still did not have an effective procedure or best practice in formulating court suits linked to discrimination of elderly persons in the delivery of patient care (29). It seems that the majority of Lithuanian elderly do not use legal means.
- v) There is a lack of complaints in the Office of the Equal Opportunities Ombudsperson in spite of the Provision 13 of the European Charter of Patients’ Rights is the ‘Right to Complain’ (11). In Lithuania, on 1 January 2005, a new Law on Equal Treatment came into force, guaranteeing the right to file complaints to the Equal Opportunities Ombudsman in cases of discrimination on grounds of age, sexual orientation, disability, race and ethnic origin, religion or beliefs (30). The ombudsman is a pre-litigation body in Lithuania for discrimination cases. Until now, the ombudsman service had only one case regarding age discrimination in health preventive programs (31). An analysis of the webpage of the ombudsman service revealed that almost all information, complaints and researches are devoted to age discrimination in the labour market.
- vi) In 2015, Lithuania created an ‘Inter-institutional operations plan for promotion of non-discrimination’ for the period 2015-2020, the main aim of which is to raise public awareness and foster respect for human beings. The plan recognized: *“Lithuanian public awareness is still too low, only a small proportion of the population knows where to go for fighting discrimination”* (32). The same is demonstrated in our findings. In interviews, ‘I do not know what to do’ was repeated in almost all conversations. Furthermore, in the action plan there are lots of general and specific steps and recommendations to act in fighting age discrimination; but this does not ensure that educational activities will reach those persons

who discriminate against the elderly in patient care. This type of discrimination is not mentioned in the action plan, and among actors (implementing authorities) there is no inclusion of the Ministry of Health. Implementing authorities are: Ministry of Social Security and Labor, Ministry of Education and Science and Ombudsman.

vii) There is a lack of institutions and organizations that provide legal help for elderly persons in resolving disputes and defending their rights in health care facilities. We did not find elder law clinics or older persons' rights protection services.

viii) There is a shortage of easy, understandable, and easily-obtainable information for elderly persons regarding their rights. We did not find web pages or specialized easily understandable, and obtainable information for elderly. To prove discrimination against elderly in legal cases is often challenging: A citation of the chief of the Lithuanian Supreme Court in 2007 may serve: *"There is no racial discrimination in Lithuania, <...> there are some complaints for some not-equal treatment in other spheres, but then proceedings are completed and discrimination is not proven"* (33).

Analysis of the interviews

The initial idea of the study was to gather information from elderly patients who were most in need of care as they required long-term care around-the-clock. However, what the family members provided as their experience of taking care and of being patients themselves, broadened the scope of the study. Thus, information about discrimination not only of the bedridden people, but also of healthier old people was gathered. In spite of all the interviewees reporting their experience as patients, the research team will further on call the two groups "patients" and "informal caregivers" according to their social roles. As concerns the discrimination because of age, there was no difference between the two groups found in what they were telling about themselves as patients, therefore, the findings about ageism are presented for both groups together.

The analysis of the interviews with patients and their informal caregivers revealed manifestation of discrimination due to age. Older persons very often confronted with violation of their rights as a human and as a patient to receive health care services and proper treatment. They often were ignored and were not treated seriously. Their right to information was violated and their right of participation in the process of decision making regarding to their own health situation was ignored. An older person with special needs (overweight) was left without appropriate care, because hospitals and elderly homes are poorly equipped and do not even have simple hoists. The detailed manifestation of discrimination and ageist behaviour revealed in the interviews is presented in Table 1.

Table 1. Ageist behaviour and manifestation of discrimination

Ageist behaviour	Manifestation of discrimination
Violation of the patients' rights to health care because of their age	<i>"The nurse is talking [to me, the caregiver] on a phone: '87 years old! And you want our doctor to pay a home visit to such a patient!? No, he [doctor] won't come. And it's illegal for me to provide infusion therapy without a prescription of the doctor.' And what should I do?" (Daughter, 67 years old, site 1).</i>
Violation of the patients' rights to the information because of their age	<i>"Nobody really cares to explain to you in what case you are eligible for rehabilitation services. The doctor says 'you are too old to understand'" (Spouse, 82 years old, site 1).</i>

<p>Ignored or not taken seriously because of their age</p>	<p><i>“I am not able to talk with the doctor about my mother’s condition. When I go for a consultation I get the only answer ‘Such an age [94 years old]!’ She even said to me, ‘in your seventies you want to be healthy?’ And I got so angry at that moment. Our town is small; we know each other. She is only several years younger than I am and she thinks that she is young! I tell her about my condition and she is not even listening. I never get any prescription. If not for our pharmacist, my mother would have been dead. My mother had a very bad erysipelas. And only the pharmacist told me that there is a special antibiotic, but the doctors usually do not prescribe it. I went to the doctor and insisted that she give the prescription for this medication. She was very unpleasant, but gave the prescription. And my mother got better straight away. But if I did not know about this type of medication, I would have never got it.” (Daughter, 70 years old, site 6).</i></p>
<p>The system serves only the interests of the system when the client is old, overweight and has special health problems</p>	<p><i>“The family doctor did not even come and look at her [mother]. <...> She said she has too many patients registered! Then she [doctor] wrote a referral to a hospital for treatment without seeing her. She [mother] did feel very bad, she was coughing up to suffocation. And my mom, she weighs 120 kg. <...> We went [to the hospital] to look for an illness in the lungs, and ended up in Vilnius [the capital] to do a computer tomography of the intestines, because they came up with an idea that there is a tumour in the intestines. But nobody hospitalized her, and the night was approaching! So I called the nurse of the integrated care team at 8.30 pm: “What should I do? Nobody hospitalizes us. And how am I supposed to take my bedridden mother who weighs 120 kg home?” Everything went on through the phone: send her, bring her, go... The nurse somehow arranged that an ambulance brought us back from Vilnius, so we were finally back in a district hospital at 2.30 am. And here again I hear: “We are not going to hospitalize her; she is old and her condition is too severe.” And they sent us back home. And I think to myself, what I should do now? My mother was dragged around through half of Lithuania and now I have her back at home with the inflammation of the lungs on my own” (Daughter, 65 years old, site 2)</i></p>
<p>When the patient is old, the doctor is reluctant to visit that patient with acute disease at home.</p>	<p><i>“<...> in April it happened that the doctor refused to visit my wife. Over the weekend my wife had gotten even worse. On Monday I went to [our] ambulatory centre to ask for a doctor’s visit. And there I was told that “today we do not have any times free for registration; for tomorrow we also cannot register. And from the first of May our doctor leaves for the holiday”. It felt like a mockery. And in the cases of acute conditions they [personnel of primary health care centre] have to take the patient in without any registration. In the waiting room there were no patients at all. Then I asked, “maybe now she [doctor] could come and examine her [my wife]? We live so close, just across the street. It would take only a few minutes to come and examine.” And her answer was, “No, I cannot leave the ambulatory”. And at the same time there were two nurses there sitting. You realize how it is? They do not care about old patients. What should we do? The fever was very high. I called for an ambulance. The ambulance took her to the hospital. And there in the hospital, she, having pneumonia and high fever, had to stay in the corridor on a transfer trolley for almost over twenty-four hours. The hospital could not refuse to</i></p>

take her in with high fever... ” (Spouse, 78 years old, site 1)

How do the older persons deal with the experience of ageist behaviour? As findings reveal, in most cases the older persons recognize ageist behaviour, but do not perceive it as a violation of their rights. Instead of trying to change anything, the people use emotional coping and remain with the feeling of helplessness. The findings disclosed that older persons face certain barriers that prevail on taking legal action in order to protect their rights to proper medical care. Among the barriers were internal barriers, health limitations, readiness and willingness of legal representatives to identify ageist and discriminatory behaviour and to represent the older person in a legal action based upon the discrimination (Table 2).

Table 2. Barriers in taking legal actions to protect the rights of older persons to proper care

Barriers	Description of the barrier
Health state limitations	<i>“...at this age you are not supposed to go to fight in the courts. [In order] to go to the court and to fight you ought to have good health and a lot of strength.” (Woman, 75 years old, site 1).</i>
Prolonged court processes	<i>“You need help here and now and not at the time when the process will be over and the court will decide. People might be in the suit for years there, and what result does it give? <...> And on the other hand, the winning of the court after half of a year or a year might be too late. By that time my husband or I myself might be below ground.” (Spouse, 70 years old, site 4).</i> <i>“There were two court processes [about using the handicapped spouses’ money for nursing]. The procedure seems quite simple, but it took half a year <...> And you have to live now, to buy medications and nursing items now. You have to live your life now.” (Spouse 78 years old, site 1)</i>
The lack of positive experience in dealing with the courts	<i>“The old person has no chance to win the court. In our courts the justice is on the side of the one who has more money. It is as simple as that...” (Man, 77 years old, site 2)</i> <i>“... I had already gone through the court in order to get the permission to use her money for her care. After her stroke she is not able to go to the bank or to sign [documents]. Her speech is limited. <...> There were two court processes. The procedure seems quite simple, but it took a half of a year <...> And you have to live now, to buy medications and nursing items now. You have to live life now. And what the result was: the decision that I can take from her account only 1400 Euro - even though at the time I had already spent over 1700 Euro just for her medications. If you want more money, you have to appeal to the court from the very beginning again. And they questioned my daughter and my son, and they both [daughter and son] were not against it. But still such decision.” (Spouse, 82 years old, site 1)</i>
The lack of special knowledge	<i>“If you want to fight for justice in the court, you have to have</i>

	<i>knowledge. These things are not for an old person.” (Woman, 71 years old, site 2).</i>
Need of other resources	<i>“You need somebody who could drive you to the court. And not once, but constantly through all the procedure. And at the moment I feel lucky that my daughter and son-in-law drive me to the doctor or to the shop, or to the church. And you would additionally ask to drive to the court? Everybody is busy with their own affairs and duties.” (Women, 74 years old, site 5).</i>
The lack of recognition of the discrimination even by lawyers	<i>“And regarding the court... Now I think to myself. My son-in-law is a lawyer. And he has never mentioned the possibility of the court. He knew our situation in details; he saw everything. Apparently he really knows that the court cannot help there. And he is really good at those things...” (Spouse, 76 years old, site 10)</i>
Inner barriers and fear of consequences to be left without any care	<p><i>Researcher: “Have you ever thought of looking for justice [regarding being discriminated by the doctor] or looking for another doctor?”</i></p> <p><i>“I have never thought about it... And when I think now, I realise that I would never do it. I would really feel uncomfortable regarding the doctor. I know her and she knows our family for so many years. And you are used to her and she knows all my health problems. Somehow you cannot go into the conflict [with the doctor]” (spouse, 76 years old, site 10).</i></p> <p><i>“If you start to conflict, you may stay without any help. And what should one do in such an age and health condition. You completely depend on the doctor. She prescribes medications... And in our ambulatory she is the only doctor.” (Woman, 78 years old, site 9).</i></p>
The lack of a patient (human) rights-based approach in all policies, lack of education, and the lack of intersectoral work	<i>“...I could not imagine that it would be hard to take care of your own mother? She raised us, so can't I now take care of her? It is five years now [since then]. <...> She cries day and night: mum, mum. You don't get if she has pain, or not. This cry, - it seems I will get crazy. When I cannot bear it anymore, I go out, walk around with my head in my arms, and come back. I used to hire people [to nurse] <...> but nobody wants to stay with such a hard patient. They stay for a month and leave. Where haven't I looked for help? <...> The answer was that we understand that it is hard for you, but it is your mother and you have to take care of her.” (Daughter, 66 years old, caregiver of 91- year- old mother, site 8).</i>

For the caregivers, taking care itself is already a huge emotional and physical overload. *“Well, when I get tired at night, I think to myself sometimes, “God, oh, God”... [...] The nursing is very difficult. You cannot leave anywhere. I step out, sit on a bench for a while and back into the house. Oh, and I go to the shop. I long for the fresh air... He is sick for 8 years already. You can imagine what it means to stay with a patient for so many years” [she is moved and gets tearful, cannot talk for some time] (Spouse, 74, site 16).*

It can be rewarding experience when you help, but there is ample research about caregivers feeling depression, somatic disorders and the like (35,36). When somebody is discriminated and does not receive proper medical care, s/he can already feel disappointed and rejected.

When you additionally do not get help with the one you take care of, the helplessness that you feel is double, because you have to see the suffering of a person close to you. The question “*and what should I do?*” without finding appropriate answer and with the feeling of helplessness was very often on the lips of the caregivers in the study.

Some participants of the study had interesting suggestions regarding how the situation could be changed to a less-ageist attitude. One of them suggested that the problem was that the fight against ageist behaviour was seen as a private matter and it has to be made into a public one.

Moreover, because of their homebound, bedridden situation the people are not able to take proper care of themselves; therefore it is improbable that they would additionally fight against discrimination. As concerns the carers, having to deal with the situation where the sick relative totally depends on you made them learn a lot about nursing, filling appropriate documents, achieving that help is provided - and this round-the-clock job without holidays often left them exhausted, was causing health problems, and did not allow to fight for change against discrimination: there were other, more urgent problems at hand and not enough resources to deal with everything. Even people with political positions could not achieve change in patient-care, in spite of writing about the situation extensively (Rūta Vanagaitė, active politician: She used her position in parliament to change the situation of people, who are dependent and need home care. She initiated discussions on the topic and raised the problems in media. Even wrote a book. Vanagaitė R. Pareigos metas [Time of duty], 2014 [In Lithuanian]). Therefore it came as a natural suggestion, that there is a need for professionals such as social workers, who would be legally entitled to act against discrimination based on age: *“I think that an older person has to have a legal representative such as a social worker. The social worker could present cases of violation of the rights of an older person. Social workers should be entitled to file a suit to the court when an older person is left without care or when a patient has to take care of another patient at home without formal support and without proper attention of doctor and nurse - in such cases like my situation was [when I was caring for my late husband]. Me, with a heart pacemaker, had to take care of my bedridden husband for over three months. I had to wash him, to lift him, and day and night to nurse him on my own. After such an intensive care I walked wobbling. Thanks God, he died in time”* (78 years old women, site 5).

Summary of the empirical findings

- i) Discrimination is not perceived as such and often is considered a lack of attention.
- ii) The fear to lose doctors' friendly support dominates, especially in rural areas, where only one doctor works.
- iii) There is no elderly-orientated or easily-operational legal information that clearly states steps to fight discrimination in patient care.
- iv) There is a lack of confidence in justice, courts, and institutions.
- v) The results of the study disclose the following barriers which the elderly in Lithuania face:
 - a) lack of recognition of the phenomenon of discrimination against the elderly in patient care;
 - b) lack of information for complaining and fear of consequences of complaining;
 - c) deficiencies and uncertainties of laws and regulations devoted to discrimination;
 - d) a high level of burden of proof in court cases and lack of good practices;
 - e) lack of a patient (human) rights-based approach in all policies and in education as well as the lack of intersectoral work.

Discussion

While other authors (35) often discuss how to fight hidden discrimination, we found it necessary to speak about open discrimination of elderly patients. The review of court cases, and more specifically interviews disclosed that the phenomenon of discrimination is neither perceived nor recognized. On the contrary, findings show that wide and open discrimination against elderly persons is manifest in patient care. In line with discussion by Williams in 'Age discrimination in the delivery of health care services to our elders' (36), we found that the main barrier to changing practice still is the lack of recognition.

In regard to the second important barrier, the lack of information and fear of consequences, Clough and Brazier asked similar questions in their work 'Never too old for health and human rights?' (35). They cite barriers in the context of the United Kingdom: The elderly patients "may not complain because of a fear of consequences, for example, that they will be evicted from their care home if they do, may not complain because they lack confidence, may feel they are 'just making a fuss', may find there is a lack of accessible complaints, mechanisms or information about how to complain, may have particular communications/language difficulties or may face limited access to legal aid providers or be limited by the scope of legal aid, or may be put off by complex legal procedures such as Conditional Fee Arrangements" (35).

This comes close to our empirical findings: the lack of information and especially the fear of consequences - are additional major barriers in Lithuania. Differently from the UK context, the fear of consequences can be explained in Lithuania by 'renter mentality and conformity that are lingering of soviet society mentality' (37) because the older generations in Lithuania lived during the Soviet period (1940-1990). We found that elderly persons do not trust courts and they do not see any possible real way to change the system. They do not know who can help them or who can inform them. They need health care now, not after long-lasting, expensive litigation. They believe that a doctor is the only person who could help them and that is why they do not want to risk losing their doctor's favour.

The third barrier in Lithuania is the deficiencies and uncertainties of laws and regulations devoted to discrimination. In this study we found that in 2004, when entering the European Union (EU), Lithuania changed or supplemented laws according to EU requirements. In most laws, non-discriminatory sentences were added. However, the implementation of laws, in general, is a real issue. Perhaps it is due to a lack of brave and new practice for forming decisions of the Lithuanian Supreme Court. Lithuanian laws should be written more clearly; their examination revealed a lack of precise articles in two basic laws (27,28) that should indicate the way for complains and, ultimately, the Constitution of Lithuania does not pay attention to age discrimination at all.

In line with the European Union Agency for Fundamental Rights finding that 'interviews with legal experts, equality bodies and health ombudsmen indicate that proving that a discriminatory act has taken place is often challenging for plaintiffs and their lawyers (38), we found that the lack of court cases is the result of the difficulty to prove discrimination, and *vice versa* the difficulty of the burden of proof is the result of the absence of successful litigation. There is one possible solution: in Lithuanian civil law court cases, the aim of averment is a court's reasonable belief of existence or non-existence of certain circumstances (Art.176) (39). That is why anti-discriminatory policies could educate judges to see discrimination more often. Also more frequent complaints (starting with civil cases) would slowly change the practice and burden of proving in civil and administrative cases (including ombudsman's procedures).

Finally, a change in policy regarding a human rights approach influencing education and fostering intersectoral coordination and cooperation in terms of health in all policies would

accelerate the already visible slow movement forward as regards the European context. Tonio Borg, ex-EU Commissioner for Health, said: *“I believe health is for all. Everybody should have access to good quality healthcare regardless of gender, age, race, and sexual orientation, type of condition, social status, education, or country of residence. For this to become reality, we need to fight discrimination in health”* (40). Unfortunately, the new Lithuanian Action plan for “Healthy Aging” (32) that derived from the Strategy and Action Plan of Healthy Aging in Europe, 2012-2020 (41) interprets ‘Healthy Aging’ from a non-human rights perspective and is in itself discriminatory. Its main focus is to inspire the elderly to be active, as a cause of healthy living, not as a consequence of healthy living. There is a policy deficiency regarding a non-active, almost-disabled or very old person who cannot be active. Lithuanian ‘Healthy Aging’ itself has to tackle discrimination and health inequalities in its approach and focus more on ‘strengthening health systems, in order to increase older people’s access to affordable, high-quality health and social services’ (41).

One of the reasons for the incomplete implementation of human rights in elderly patient care is likely the non-binding character of many conventions and charters instead of binding legislation. The European Charter of Patients’ Rights of 2002 (4) contains 14 provisions, the second being the ‘Right of access’: *‘The health services must guarantee equal access to everyone, without discriminating on basis of financial resources, place of residence, kind of illness or time of access to services’*. It seems that Lithuanian lawmakers are afraid of the word ‘guarantee’ and its consequences, especially when the talk is about financial resources.

This can be illustrated by the words of the Secretary-General to the UN General Assembly: *“Older persons suffer discrimination in health care and tend to be overlooked in health policies, programmes and resource allocation”* (42). Or by the research, where Aleksandrova investigating the question of financial resource allocation in her study *‘Should Age be a Criterion for the Allocation of Health Resources?’* (43) gives different arguments ‘for’ and ‘against’ focusing on the usefulness of the elderly.

The Universal Declaration on Bioethics and Human Rights of 2005 is not legally binding either, but has expedient content such as its Article 11: *‘No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms’* (44). Even binding instruments, as the International Covenant on Economic, Social and Cultural Rights with its article 12 *‘The States Parties to the present Covenant (e.g. Lithuania) recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’* do not change the situation.

The crucial point, however, is the lack of successful practice in the European Court of Human Rights (ECHR) (34). Examples of ECHR cases show that Lithuania has no strong outside incentive or rather pressure, different from the period of accession to the EU in 2004. The fear of sanctions/consequences for not complying with the *Acquis Communautaire* was a powerful incentive. But later, in 2005, the Protocol 12 to the European Convention on Human Rights – devoted to the extension of prohibition of discrimination – was not signed by Lithuania (45).

The Americas likely will become the first region in the world to have an instrument for the promotion and protection of the rights of older persons (46). If it is ratified, the member states will “adopt and strengthen such legislative, administrative, judicial, budgetary, and other measures as may be necessary to give effect to and raise awareness of the rights recognised in the present Convention, including adequate access to justice, in order to ensure differentiated and preferential treatment for older persons in all areas” (47). This is a good example setting standards for a stronger legislation.

Most barriers - not only in Lithuania - seem to be concerned with policy. Now it is time to ask about the place of elderly people in public health policy. First, there is an “inner level” question: what person is able to notice the discrimination and the barriers? Answer: a person who is trained to notice. Our study revealed a big gap between the occurrence of discrimination and fighting that discrimination in the health system. We agree with the statement by Bjegovic-Mikanovic et al. that: ‘...public health education needs to include a wider range of health-related professionals including: managers, health promotion specialists, health economists, lawyers and pharmacists. <...> Investing in a multidisciplinary public health workforce is a prerequisite for current challenges’ (48).

Secondly, there is an “external level” question. When asking how/where can the barriers be removed, we find that in a State, where there are appropriate and enforceable instruments and an older person-friendly scene in which to enforce them. Historically, from the ancient times it was a taboo to complain about the doctor’s work; it appears that it is still a taboo to complain about human rights violations. The State must improve the legal basis and have a strong will to help improve and protect older persons’ rights in all spheres.

Thirdly, there is a question dealing with information and leadership. The need for a workforce that is educated in the needs and rights of elderly persons (lawyers, judges, health care providers, politicians, and even the church clerks) is obvious. These professionals need multidisciplinary knowledge in order to think “out of the box”. Good practices from other countries for elderly legal consultation can be used, for example elder law clinics (49) and ‘e-help’ as a compilation of useful information (50). The burden of leadership is to make this a reality that belongs to everyone.

However, we are aware of the limitations of our research. The narrative literature review was performed in order to show the need to solve the problem of discrimination and because of scarcity of prior research in Lithuania. However, a systematic review of good practice abroad might have yielded more specific evidence. Also a bigger sample size might have allowed comparing the group of patients with the caregivers. Nevertheless even our small study reveals serious violations of elderly patients’ rights and should arouse the attention of politicians, stakeholders and professionals and help to initiate further studies to analyse the quantity and quality of human rights neglect in elderly patient care.

Conclusions

In spite of the obvious limitations of our study, we were able to identify three main barriers that blockade improvements in elderly patient care:

- Recognition of open and hidden discrimination of elderly patients.
- Lack of information and fear of consequences experienced by patients and caregivers facing discrimination and considering complaint.
- Deficient non-binding legislation and court practice.

In consequence this study disclosed the need to:

- Encourage training of health care professionals. The burden of leadership has to be assumed by universities and public health professionals;
- Encourage training of legists and lawyers in expanding knowledge and skills in human rights in patient care;
- Incorporate a new article in the ‘Law on the rights of patients and compensation for the damage to their health’, clearly stating where to complain in case of discrimination;
- Create a web page and brochures with readable and understandable information for elderly persons and their families and caregivers;

- Establish legal consultation and mediation cabinets in health care facilities;
- Establish an older persons' rights protection service under the Ministry of Social Security and Labor in close cooperation with the Ministry of Health;
- Promote sustainable results by incorporating a human rights-based approach regarding elderly persons in all policies.

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